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(Degree)

博士 (保健学)

(Date of Degree)

2021-03-25

(Date of Publication)

2022-03-01

(Resource Type)

doctoral thesis

(Report Number)

甲第8050号

(URL)

<https://hdl.handle.net/20.500.14094/D1008050>

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博 士 論 文

Impact of nurses' providing a simple health check for the family caregivers of patients with severe mental illness on the reduction in caregiver burden

（重度精神疾患患者の家族介護者に対する看護師による簡単な健康
チェックが介護者の負担感軽減に与える影響）

令和 3 年 1 月 18 日

神戸大学大学院保健学研究科保健学専攻

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Impact of nurses' providing a simple health check for the family caregivers of patients with severe mental illness on the reduction in caregiver burden

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Abstract

A randomized controlled clinical trial was conducted to determine whether a simple health check by a visiting nurse could reduce the burden on family caregivers of patients with severe mental illness, namely schizophrenia or mood disorders. The severity was characterized by patients' disease duration or resulting disability. Family caregivers were randomly assigned to an intervention group (n=21) or a control group (n=18). Caregivers in the intervention group received a simple health check: blood pressure and pulse assessment and questions regarding mood, sleep, and fatigue, on every visit for 2 months (total 4–8 times). The Japanese version of the Zarit Caregiver Burden Interview (J-ZBI) was used to assess caregiver burden. After the intervention, the total J-ZBI score in the intervention group was not significantly different from that in the control group. However, the total J-ZBI score in the intervention group decreased significantly after the intervention, while no change was observed in the control group. The scores of three J-ZBI sub-items related to personal burden decreased significantly for the intervention group after the intervention. These results suggest that simple health checks conducted by visiting nurses for family caregivers of patients with severe mental illness may reduce the burden on family caregivers.

Key words: Caregiver burden, Family caregivers, Health check, Vital signs, Visiting nurses, Severe mental illness, Schizophrenia, Mood disorders

Introduction

One of the influences on the burden of family caregiver of people with mental illness is the caregivers' own health condition¹⁾. Family caregivers are worried about their own health²⁾³⁾, but often do not have enough time and mental capacity to take care of themselves or visit medical institutions when necessary as they are too occupied caring for their patients⁴⁾. The unhealthy condition of family caregivers leads to their feeling of burden. Further, caregivers, especially those living with patients with mental illness including schizophrenia or bipolar mood disorders, often experience the severe changes in the patient's symptoms and the sudden episodes of patient's violent behaviors⁵⁾, which affects their family's mental and physical health²⁾³⁾, consequently resulting in poor caregiver health⁶⁾⁷⁾.

The Japan Visiting Nurse Foundation provides a detailed description of the contents of nursing services at home for individuals with illness⁸⁾⁹⁾. Support for family caregivers is a component of visiting nursing services, and nursing consultation in the caregiver's daily life is considered important. General health checkups are well known to trigger self-care behaviors for health in the general population¹⁰⁾. Health checkups by a visiting nurse can also promote caregivers' self-care behaviors for health¹¹⁾.

In addition, families of patients with mental illness experience characteristic social isolation due to prejudice, stigma, or limited support¹²⁾. Paying attention to themselves through health checkups may produce the following experiences in caregivers: 1) becoming aware of the importance of family caregiver's health, 2) perceiving being supported by visiting nurses, 3) trying to find more effective coping strategies in consultation with visiting nurses. In this study, we employed a simple health check — blood pressure and pulse¹³⁾ assessment and questions on mood¹⁴⁾, sleep¹⁵⁾, and fatigue⁶⁾ — as a flexible intervention to be used alongside nursing interventions for patients. Therefore, we hypothesized that checking the health of family caregivers would reduce the burden of caregiving on these persons. Accordingly, the purpose of this study was to examine the effects of a health check conducted by visiting nurses on caregivers living with patients with severe mental illness.

Methods

The subjects of this study were family caregivers living with a severely mentally ill patient who received home nursing care once a week or every two weeks between September 2013 and March 2015. Patients with severe mental illness were defined as those with impaired social functioning and a diagnosis of schizophrenia or mood disorder as defined in the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, excluding dementia. Although Global Assessment of Functioning (GAF)¹⁶⁾ or another scale was not always used, the attending doctors determined that visiting nursing services were required because of the severity of the symptoms and social functions of patients, and then ordered a visiting nursing station to provide nursing care. The definition of the study subjects was explained to the nurses at the visiting nursing stations, and the caregivers were recruited in the following steps.

If there was more than one family caregiver, the person with the most central role was selected. Family

caregivers were excluded if the family caregiver had a severe mental illness or cognitive deficit that made it difficult for them to communicate with others or to complete the questionnaire.

Thirty-two visiting nursing stations belonging to the National Association for Visiting Nurse Service in Japan, mainly in the Kinki region, were called to inform them of the purpose of the study. Twenty-one visiting nursing stations expressed interest in the study, including 20 in the Kinki region and 1 in Chiba Prefecture. These 21 stations received written and oral information from first author (S. N.) regarding the purpose, procedure, and ethical consideration of the study, which led to 13 visiting nursing stations cooperating with this study. The attendant nurses explained the study to the family caregivers, and 47 family caregivers agreed to participate personal.

The caregivers were randomly divided using the sealed envelope method into two groups: an intervention group that received the usual services and simple health checkups by the visiting nurse, and a control group that received only the usual services. The process of the study is shown in Figures 1 and 2. The study was approved by the Ethics Committee of the Kobe University Graduate School of Medicine (approval number: 200).

In the intervention group, a simple 10-minute health check — blood pressure and pulse assessment and questions on mood, sleep, and fatigue — was administered to the caregivers by the visiting nurses on every visit for 2 months (total 4–8 times). Questions asked by the visiting nurses of the family caregivers were reviewed among the researchers, under the following conditions: 1) the questions should not have an impact on the patient, who was the primary target of home care nursing; 2) the questions should lead to the detection of family caregiver's illness, which could signal the need for an intervention; and 3) the questions should not be directly related to the research outcomes of caregiver burden and health perspectives. As a result of our review, we focused on the fact that family caregivers tend to be depressed⁽¹²⁾⁽¹⁷⁾⁽¹⁸⁾⁽¹⁹⁾ and therefore selected questions to assess depressed mood, sleep disturbances, and fatigue.

Health check notebooks were prepared (Figure 3), in which the caregivers noted the results of their blood pressure and pulse measurements and rated their sleep, mood, and fatigue using a 5-point Likert scale. The health check notebook was kept with the caregivers.

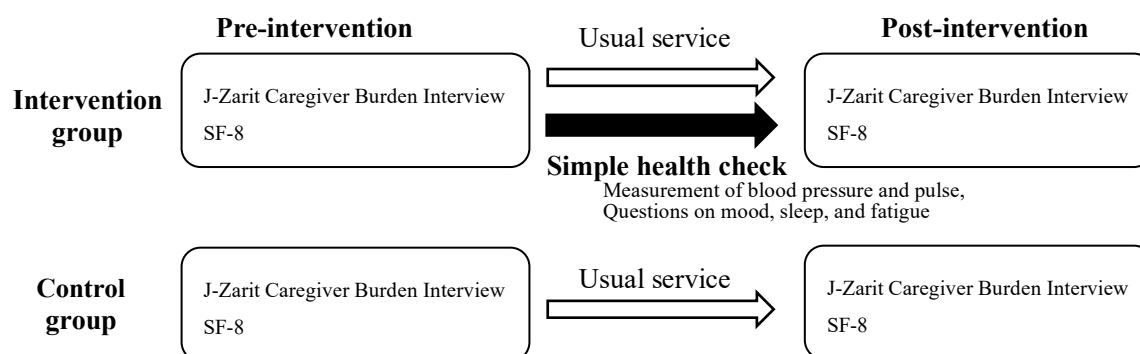


Figure 1. Intervention and assessments.

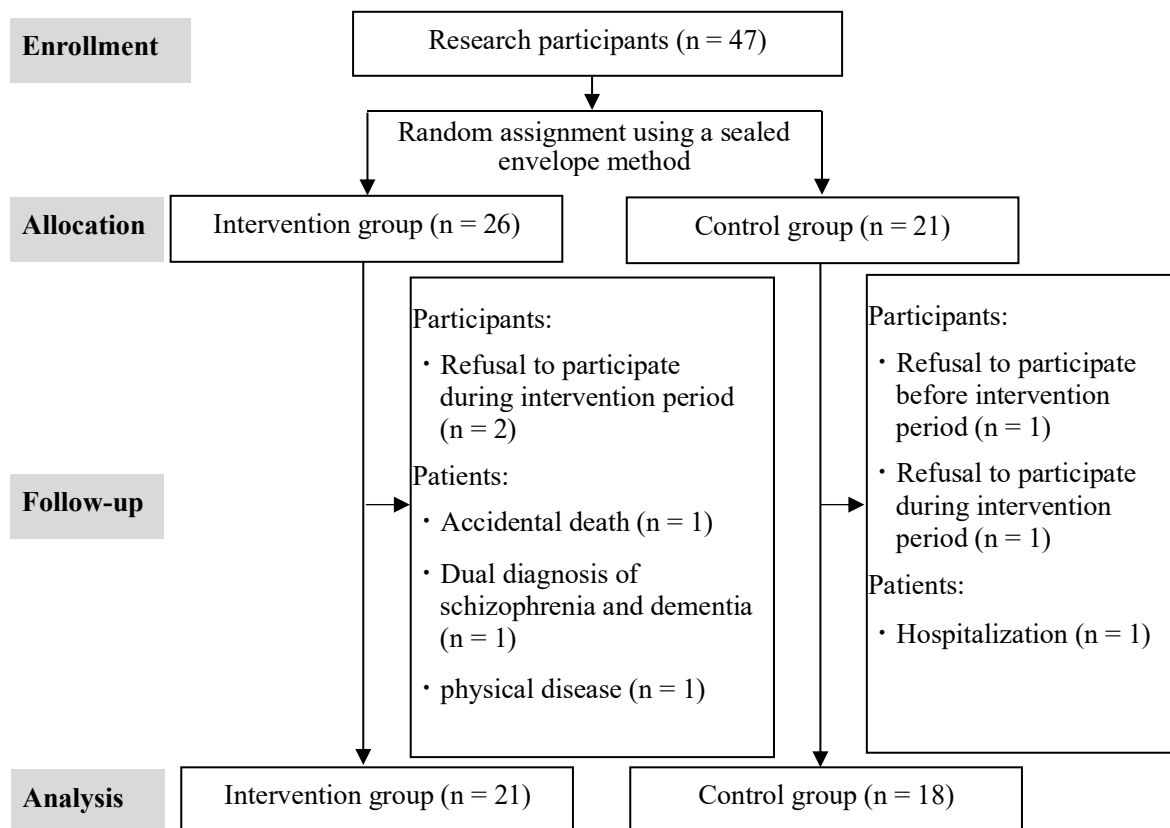


Figure 2. CONSORT flow diagram of participant status.

HEALTH CHECK	Date	/	/
Blood pressure	_____	/	_____
Pulse	_____		
	Very poor	Poor	Average
How well are you sleeping?	_____	_____	_____
How are you feeling?	_____	_____	_____
How tired are you?	_____	_____	_____
	Good	Excellent	

Figure 3. Health check notebook.

When obtaining consent for participation in the study from the caregivers, we explained the research plan using a written document, namely that this was a study to check briefly the health of family caregivers during visits. Nurses did not make any special announcement to the caregivers at the time of the visit, but

simply stated, "I will check your vitals and ask you about your physical condition and mood." The intervention procedure was standardized among the multiple intervention facilities by consistent explanation of the intervention procedure by the researcher, using the intervention protocol sheet.

To assess the effectiveness of the health check intervention, the following measurements were taken before, and after the two-month intervention. The Japanese version of the Zarit Caregiver Burden Scale (J-ZBI) was used to evaluate the sense of burden experienced by caregivers from their answers to 22 questions about the subjective burden of caregiving. The reliability and validity of this scale have been verified²⁰⁾. J-ZBI has two subscales: personal strain and role strain. While personal strain refers to "how personally stressful the experience is," role strain is "the stress due to role conflict or overload"²¹⁾²²⁾²³⁾.

The SF-8 Japanese version of the Health-Related Quality of Life Scale was used to survey the sense of health of the caregivers. The SF-8 is a shortened version of a multi-purpose questionnaire that measures health status²⁴⁾. It is scored on the same metrics as the eight subscales of the SF-36, a single-item rating scale. The SF-8 consists of eight questions, covering the topics of overall health, physical functioning, daily role functioning (physical), body pain, vitality, social life functioning, mental health, and daily role functioning (mental). The general Japanese population in 2007 had average scores of 50 on the Physical Component Summary (PCS) and the Mental Component Summary (MCS) of the SF-8; higher scores indicate better health.

The background data of participants in the two groups were compared using the chi-square test, Mann-Whitney U test, or Fisher's exact test. For the J-ZBI and SF-8 scales, the total scores or summary scores were assessed by the Mann-Whitney U test for two-group comparisons between the intervention and control groups, and pre- and post-intervention within-group comparisons were assessed using the Wilcoxon signed-rank test. SPSS Ver. 23 was used for the statistical analysis.

Results

The 47 participants, all of whom were family caregivers, were divided into two groups: 26 in the intervention group and 21 in the control group. In the intervention group: three participants discontinued participation due to problems with the patients' conditions, and two participants refused to continue participation in the study. In the control group: one patient's condition worsened during the study and the nursing visit was canceled due to hospitalization, one caregiver refused to participate before the intervention period, and one participant refused during the intervention period. As a result, there were 21 participants in the intervention group and 18 in the control group (Figure 2). No significant difference was observed in the dropout rates between the intervention and control groups ($p = 0.7155$, using Fisher's exact test) (Figure 2). There were no significant differences in the gender, age, marital status, relationship with patient, presence of other caregivers, or duration of mental illness of the patients between the two groups (Table 1).

Table 1. Participants' characteristics.

Intervention	n	Control	n	p-value
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Sex ^c		21		18	0.284
Male		4		7	
Female		17		11	
Age ^a		21		18	0.640
Years	70.5 ± 12.4	20	69.5 ± 11.6	17	
No answer	-	1	-	1	
Marital status ^c		21		18	0.586
Married		20		17	
Unmarried		1		1	
Relationship to patient ^b		21		18	0.441
Spouse		3		6	
Mother		15		10	
Father		1		1	
Brother/Sister		1		1	
Child		1		0	
Existence of other caregivers ^b		21		18	0.054
Yes		14		6	
No		7		11	
No answer		0		1	
Patient's diagnosis ^c		21		18	1.000
Schizophrenia		19		17	
Mood disorder		2		1	
Duration of patient's disease ^a		21		18	0.811
Years	17.4 ± 11.2	17	19.0 ± 14.0	17	
No answer	-	4	-	1	

a : Mann-Whitney U test.

b : Chi-square test.

c : Fisher's exact test.

There was no significant difference in the post-intervention J-ZBI total score between the intervention and control groups. However, there was a significant difference ($p = 0.049$) in J-ZBI total score between the pre- and post-intervention comparisons in the intervention group (Table 2). A close examination of the items of the J-ZBI revealed that there was a significant difference in scores between pre- and post-intervention for question No. 5 “Do you feel angry when you are around the patient?” ($p = 0.033$), No. 8 “Do you feel that the patient depends on you?” ($p = 0.038$), and No. 18 “Do you feel that you would like to leave the care of the patient to someone else?” ($p = 0.045$). Significant differences between the two groups on these three questions specifically show that this intervention decreased personal strain, as these three questions correspond to the subscale of personal strain.

Table 2. J-ZBI scores for the intervention and control groups.

	Intervention (n=21)				Control (n=18)				Difference (p -value)			
	Pre-intervention		Post-intervention		Pre-		Post-		Pre-	Post-	Intervention	Control
	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Intervention and Control ^a		Pre- and Post- ^b	
J-ZBI_total	25.5	18	20.5	19	29	28	29.5	23	0.376	0.185	0.049*	0.325

J-ZBI_01	1	2	0.5	2	1	2	1	2	0.873	0.303	0.429	0.365
J-ZBI_02	1	2	1	2	1	1	1	2	0.942	0.919	0.873	0.414
J-ZBI_03	1	2	1	1	1.5	2	2	3	0.553	0.317	0.626	0.479
J-ZBI_04	1	2	1	2	1.5	2	1.5	1	0.592	0.346	1.000	0.317
J-ZBI_05	1	2	1	1	1	2	1	2	0.896	0.206	0.033*	0.705
J-ZBI_06	0	1	0	1	1	2	1	2	0.376	0.303	0.654	0.705
J-ZBI_07	2	2	2	2	3	2	3	3	0.017*	0.227	0.818	0.095
J-ZBI_08	3	2	2	3	3	1	3	2	0.263	0.041*	0.038*	0.527
J-ZBI_09	1	2	1	1	1	3	1	2	0.553	0.118	0.159	1.000
J-ZBI_10	1	1	1	1	1	2	1	1	0.828	0.919	0.490	0.557
J-ZBI_11	0.5	1	0	1	0	1	0	1	0.739	0.873	0.802	0.365
J-ZBI_12	1	2	0.5	1	1	1	1	2	0.376	0.409	0.103	0.205
J-ZBI_13	1	2	0	1	1	1	1	1	0.806	0.633	0.083	0.365
J-ZBI_14	1.5	2	1	2	3	1	2.5	2	0.005*	0.028*	0.057	0.012*
J-ZBI_15	1	3	1	2	1.5	3	1.5	3	0.965	0.361	0.223	0.507
J-ZBI_16	1	2	0	1	1	2	0.5	2	0.592	0.553	0.190	0.395
J-ZBI_17	1	2	1	2	1	2	1	2	0.806	0.806	0.482	0.517
J-ZBI_18	0	1	0	1	0.5	2	0.5	1	0.276	0.166	0.045*	0.546
J-ZBI_19	1	1	1	2	1.5	1	1	2	0.633	0.331	0.713	0.725
J-ZBI_20	0.5	1	0	1	1	2	0	1	0.443	0.851	0.365	0.329
J-ZBI_21	0	1	0	1	0.5	1	0	1	0.443	0.496	0.654	0.589
J-ZBI_22	2	2	1.5	1	2	1	1	1	0.761	0.873	0.160	0.941

J-ZBI: the Japanese Version of the Zarit Caregiver Burden Interview.

IQR: Interquartile range.

a : Mann-Whitney U test.

b : Wilcoxon signed-rank test.

* : $p < 0.05$, significant difference between the two groups.

J-ZBI_01 : Do you feel that the patient asks for more help than he/she needs?

J-ZBI_02 : Do you feel that because of the time you spend with the patient that you don't have enough time for yourself?

J-ZBI_03 : Do you feel stressed between caring for the patient and trying to meet other responsibilities for your family or work?

J-ZBI_04 : Do you feel embarrassed over the patient's behavior?

J-ZBI_05 : Do you feel angry when you are around the patient?

J-ZBI_06 : Do you feel that the patient currently affects your relationships with other family members or friends in a negative way?

J-ZBI_07 : Are you afraid what the future holds for the patient?

J-ZBI_08 : Do you feel that the patient depends on you?

J-ZBI_09 : Do you feel strained when you are around the patient?

J-ZBI_10 : Do you feel your health has suffered because of your involvement with the patient?

J-ZBI_11 : Do you feel that you don't have as much privacy as you would like because of the patient?

J-ZBI_12 : Do you feel that your social life has suffered because you are caring for the patient?

J-ZBI_13 : Do you feel uncomfortable about having friends over because of the patient?

J-ZBI_14 : Do you feel that the patient seems to expect you to take care of him/her as if you were the only one he/she could depend on?

J-ZBI_15 : Do you feel that you don't have enough money to take care of the patient in addition to the rest of your expenses?

J-ZBI_16 : Do you feel that you will be unable to take care of the patient much longer?

J-ZBI_17 : Do you feel you have lost control of your life since the patient's illness?

J-ZBI_18 : Do you feel that you would like to leave the care of the patient to someone else?

J-ZBI_19 : Do you feel uncertain about what to do about the patient?

J-ZBI_20 : Do you feel you should be doing more for the patient?

J-ZBI_21 : Do you feel you could do a better job in caring for the patient?

J-ZBI_22 : Overall, how burdened do you feel in caring for the patient?

Table 3. SF-8 scores for the intervention and control groups.

	Intervention (n=21)				Control (n=18)				Difference (p-value)			
	Pre-intervention		Post-intervention		Pre-		Post-		Pre- Intervention and Control ^a	Post- Intervention and Control ^a	Intervention Pre- and Post- ^b	Control Pre- and Post- ^b
	Median	IQR	Median	IQR	Median	IQR	Median	IQR				
PCS	45.10	10.2	47.19	6.94	50.52	7.25	44.64	13.7	0.149	0.331	0.421	0.017*
MCS	47.00	7.24	45.88	7.70	47.06	9.23	47.93	10.2	0.942	0.874	0.809	0.619

SF-8: Short-Form Health Survey-8, PCS: Physical component summary, MCS: Mental component summary.

IQR: Interquartile range.

a : Mann-Whitney U test, b : Wilcoxon signed-rank test.

* : $p < 0.05$, significant difference between the two groups.

There were no significant differences in the post-intervention SF-8 PCS or MCS score between the intervention and control groups (Table 3). In the intervention group, no significant difference was observed in PCS or MCS for pre- versus post-intervention comparisons.

Discussion

We could not find a significant difference in the J-ZBI total score between the intervention and control groups after the intervention period. However, the pre- and post-intervention comparisons showed a significant decrease in J-ZBI total score in the intervention group, while there was no change in the control group. In the intervention group, three sub-items of the personal strain subscale of J-ZBI showed significant reductions in pre- and post- comparison. These results show that the implementation of a simple health check for family caregivers can be effective in reducing their care burden, in particular, the personal strain component of care burden.

Family caregivers of patients with severe mental illness are less likely to pay attention to their own health due to insufficient time and mental capacity to take care of themselves^(6,7). The personal strain refers to the sense of burden arising from the care itself⁽²³⁾. In this study, the significant decrease in Question No. 5 scores (“Do you feel angry when you are around the patient?”) suggested that the health checkups by the nurses might have reduced feelings of burden in the family caregivers. The caregiver could have experienced relief from their sustained tension and anxiety in daily life through the regular health checks, and especially through the repeated experience of being considered by the visiting nurses. The significant decrease in scores of Question No. 8 (“Do you feel that the patient depends on you?”) and No. 18 (“Do you feel that you would like to leave the care of the patient to someone else?”) suggested that improvements occurred in the family caregivers’ cognitive distortion with respect to patients following the health checkup intervention. Caregivers of patients with severe mental illness often experience social isolation and have a cognitive distortion toward their patients^(12,25). The relationships with visiting nurses brought about by health checks could have decreased the feelings of isolation experienced by the caregivers⁽²⁶⁾, resulting in reduced cognitive distortion of caregivers toward their patients.

The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”⁽²⁷⁾. When this definition of health was applied to family caregivers of patients with severe mental illness, it was clear from various previous studies that family caregivers do not experience well-being in their daily lives, and hence, cannot be considered healthy^(22,25,28,29,30). Caregivers of patients with severe mental illness are affected both mentally and physically by the mere act of caring for their patient.

The simple health check, which did not require any special preparation or training/education program for nurses, can be conducted in approximately 10 minutes during a visit, and was not burdensome for the

caregiver. At present, visiting nurses are usually consulted when a caregiver may have a problem. Therefore, health checks can be conducted as a part of the current visiting nurses' services. To perform health checks for caregivers as one of visiting nurses' services, it is important that caregivers are approved as recipients of nursing services. Further studies are needed to provide evidence that health checks by visiting nurses can prevent or reduce caregivers' problems, such as improving caregivers' self-care behavior, reducing household health-care costs, and extending patients' community life.

Our working hypothesis was that health checks of family caregivers by visiting nurses would help reduce the personal strain of caregiving and maintain the sense of health among caregivers via caregivers' interactions with nurses. Reducing the burden of caregiving and maintaining a sense of health are very important among family caregivers; visiting nurses can play an active role in ensuring this, and might promote consistent self-care by family caregivers. The results of this study partially supported our working hypothesis.

Limitations of the Study

In this study, visiting nurses conducted a health check of the family members of patients with severe mental illness during a visit. It required approximately 10 minutes to perform the health check. Since the Japanese visiting nursing system sets detailed fees for visiting, it was necessary to understand the visiting nursing stations and the recipients to obtain their cooperation. As a result of the difficulty in obtaining this cooperation, relatively few caregivers could be included in the study. Accordingly, it is necessary to increase the number of participating caregivers for the verification of the effectiveness of this intervention. In addition, there was a bias in the targeted areas, so it is necessary to cover a wider area in future studies. Moreover, the short two-month duration of the intervention may have influenced the results. It is necessary to extend the study period for more extensive comparisons in the future.

Conclusions

A simple health check, such as measurement of vital signs and an interview by visiting nurses, for family caregivers of patients with severe mental illness may relieve the caregivers' total burden, and may be effective in reducing personal strain associated with the burden of caregiving. It is important that visiting nurses consider the health of caregivers as well as that of patients.

Acknowledgments

We would like to express our sincere gratitude to all of the caregivers, visiting nursing station managers, visiting nurses, and the graduate students at the Department of Rehabilitation Science, Kobe University Graduate School of Health Sciences.

Conflict of Interest

The authors declare that there is no conflict of interest.

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